

Fear, Guilt, and Discrimination in Women Living with HIV in Jakarta, Indonesia



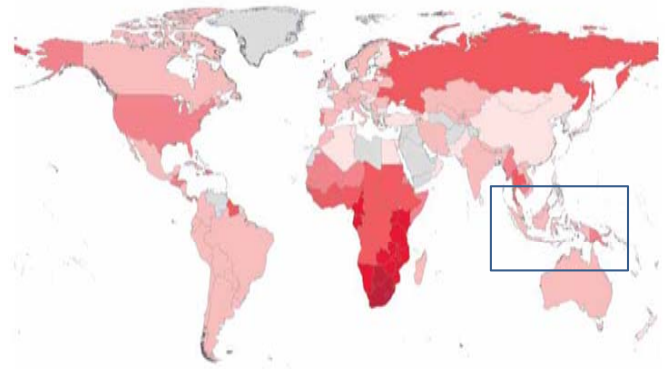
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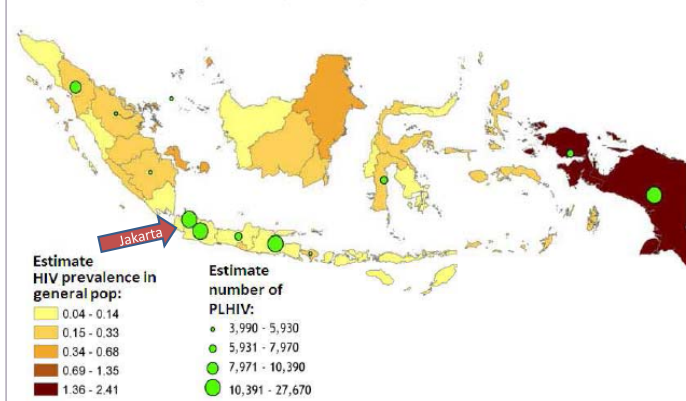


Background



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Background



Estimate HIV prevalence in general pop:	Estimate number of PLHIV:
0.04 - 0.14	3,990 - 5,930
0.15 - 0.33	5,931 - 7,970
0.34 - 0.68	7,971 - 10,390
0.69 - 1.35	10,391 - 27,670
1.36 - 2.41	

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Background

- The HIV epidemic in Indonesia is one of the fastest growing in Asia¹
- In 2009, an estimated 333,200 people were living with HIV in Indonesia and 25% were women¹
- Women were more likely to be the target of stigma, and discrimination, and were less likely to access HIV testing than men²
- A single study in Papua indicated that HIV positive women experienced high levels of stigma from their families and community members²
- A common myth that fuels stigma in Indonesia was that HIV positive women were associated with prostitution³
- No other study has examined the daily stigma experiences of women living with HIV in other parts of Indonesia

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Purpose

To understand the experiences of stigma among women living with HIV in Jakarta, Indonesia



Methods

- Semi-structured interviews were conducted with HIV positive women at a non-governmental agency in Jakarta
- Second interviews were conducted to confirm the initial findings with six participants from the original study
- Interviews were recorded using a digital audio recorder and transcribed verbatim
- Thematic analysis was used to analyze results of the study

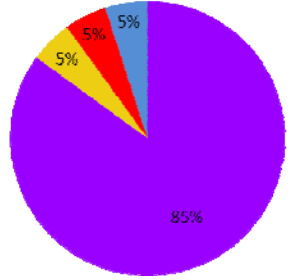
Results

Demographic of Participants

Number of Participants	20
Age	21 – 37 years (mean: 29.2 years)
Education level	10% Junior high school 80% Senior high school 10% College
Marital Status	40% married 20% remarried (10% with HIV +, 10% with HIV -) 40% widowed
Occupation	55% housewives 45% employed
Duration of Diagnosis	3 month – 8 years
Children	100% have children 70% of mothers have at least one HIV (+) child

Results

Transmission Modes



Transmission Mode	Percentage
Sexual Contact (Heterosex)	85%
Sexual Contact & Sharing Needle	5%
Sharing Needle (IDU)	5%
Unknown	5%

Results

The themes that emerged:

1. Fear of the impacts of being HIV positive

- That people will discover their HIV status and discriminate them and their family.
"If they knew...they would not stay close with me, that is what I am afraid of. I am afraid that they will avoid my children..and me as well...I think about it over and over again ...I am afraid to be avoided, discriminated..." (27 years old)
- That they will infect others
"I use a separate glass, I separate it by myself because I am afraid to infect others, although I know it will not. I am just afraid!" (26 years old)
- Of the impact of stigma on their children and other family members
"I am afraid of the impact of itespecially the psychological impacts on my son, he could be shunned by his friends" (33 years old)

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Results

2. Dealing with guilt

- For infecting their children
"I felt guilty...because of me, he became infected!" (21 years old)
- For having HIV, which could stigmatize the rest of their family
"I feel sad...because of the disease that I have, everyone is affected" (34 years old)

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Results

3. Experience with discrimination

- Self Discrimination by HIV positive women
"They will avoid me for sure since they don't know anything about this disease...they only know that promiscuous women will be HIV positive, only naughty men and women. They don't know that a housewives can be a victim." (29 years old)
"They (health care providers) still believe that shaking hands can transmit the disease or having contact with a wound. It isn't that easy." (27 years old)
- Discrimination from family
"My mother treated me differently, for example she separated my food, my drink. She put tape on it, the black one (tape), she put it on my plates, my spoons, my glass to mark it that they were only used by me." (23 years old)
- Discrimination from health care workers
"I had to wait until the last patient was called even though I came early." (27 years old)

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Discussion

- Stigma experiences are widespread in women living with HIV in Jakarta
- Personal and community misperceptions fuel the stigma behaviors
- Women with HIV have little support to deal with their own feelings and rejections by others
- Women selectively choose to associate with HIV positive partners

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Implication for Practice

- Urgently needed interventions that focus on education, coping strategies and social support for women living with HIV
- Behavioral role playing is needed to help HIV positive women to anticipate how to respond to family and community members when they learn about their HIV status
- Nationwide health education programs about HIV need to target families, community members, and health care providers
- Women need to be encouraged to seek counseling for PMTCT and family planning
- Services for children living with HIV are urgently needed

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Thank You



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